

# DRAFT Recommendations

**WORKING DRAFT FOR DISCUSSION ONLY | 11.30.23**

The following are draft recommendations that have not been endorsed by the Minnesota POLST Registry Study Advisory Committee.

## Overarching Recommendation

1. The POLST registry needs to be part of a comprehensive statewide POLST program that:
  - a. Supports shared informed decision making between health care professionals and patients along with their family and appropriate surrogates.
  - b. Ensures patients' rights are protected and their health care decisions are accurately communicated, respected, and followed.
  - c. Advances equitable access and use of POLST.

A POLST program should include education and training, a call center, and a registry. The education and training should focus on POLST discussions, decisions, and best practices; POLST registry training; and POLST public education and awareness. To achieve alignment and accountability the program should have a coordinating organization with stakeholder representation and input.

## POLST Education and Training

### POLST Discussions, Decisions, and Best Practices

2. Build upon and expand existing education and training to ensure that all health care professionals involved with end-of-life and emergency care are trained on the POLST best practices and processes. The ongoing standardized training should include:
  - a. Identifying which patients are POLST-appropriate and when the order needs to be created, updated, or reviewed.
  - b. Ensuring that POLST conversations and shared informed decision making occur between health care professionals and patients and their surrogates.
  - c. Including POLST as part of advance care planning and the Patients' Bill of Rights.
  - d. Applying POLST guidelines for valid completion.
  - e. Use of completed POLST by EMS and emergency departments.

Ongoing health care professional trainings should be developed for a variety of scenarios and health care settings to address time and availability barriers. Trainings strategies should include virtual and in person settings, just in time trainings, for CEUs, lunch and learns, etc.

3. Expand reach of currently available education and training for court-appointed guardians and other surrogates to support informed and equitable decisions.
4. Develop tools for organizational readiness to implement POLST. This includes the capacity and policies to implement the POLST and its workflow. Areas of focus should include, but are not limited to, privacy and security, collecting informed consent, billing for advance care planning (POLST discussions), and access to POLST through a patient's personal health record.
5. Medical, nursing, social work, and other professions should encourage advance care planning as part of curriculum for future and current colleagues.

## POLST Registry Training

6. Provide ongoing standardized training for health care professionals on the POLST registry including submission and retrieval, use of POLST in an emergency, access methods, and privacy and security safeguards. The trainings should be developed for a variety of scenarios and health care settings to address time and availability barriers. Trainings strategies should include virtual and in person settings, just in time trainings, for CEUs, lunch and learns, etc.
7. Develop tools for organizational readiness to use the POLST registry. This includes capacity and policies to implement the POLST registry into workflows.
8. Provide education and training to patients and their surrogates who participate in the POLST registry when/if the consumer access is implemented.

## POLST Public Education and Awareness

9. Provide an ongoing active public education and awareness campaign for POLST as part of advance care planning and, when developed, the POLST registry. The campaign should target patients, families, surrogates, and faith leaders; be inclusive of cultural, faith, disability, and other perspectives; and include the common non-English languages spoken in Minnesota (including ASL).

## POLST Registry

10. The POLST registry should require role-based access for all authorized users with their own unique account login credentials. These authorized users, include, at a minimum:
  - a. Emergency medical responders (EMR), emergency medical technicians (EMT), and paramedics that currently work or volunteer for a licensed ambulance, including advance life support and basic live support, or a registered medical response unit (MRU).
  - b. Health care professionals at hospitals, clinics, home care, assisted living, skilled nursing facilities, and hospice.
  - c. POLST registry and call center staff as needed to complete their duties.

11. Authorized users are subject to state and federal privacy and security laws and policies as applicable by role and organization.
12. Develop one or more consumer access methods to the POLST registry for patients and their surrogates who participate with the registry.
13. The POLST registry must have multiple methods to obtain POLST and ensure timely access by authorized users regardless of location or technology. The identified methods necessary to achieve statewide access are listed below. Note that to be successful each method has implementation and governance considerations and requirements. POLST registry access methods should include:
  - a. Single sign-on via EHR: POLST registry access via single sign-on through integration with an electronic health record (EHR). This method would be used primarily by health care professionals at health systems and facilities that are able to implement this type of integration.
  - b. Portal: POLST registry access through a portal/web browser. This method would be used primarily by health care professionals at health systems and facilities that are not able to utilize the single sign-on method.
  - c. Cellular phone voice: POLST registry access by calling a POLST call center, where authorized health providers would access (through a portal/web browser) the POLST registry and relay back if there is a POLST and its contents. This method would primarily be used by EMS and also available for other authorized users who do not have internet access immediately available.
  - d. Allied Radio Matrix for Emergency Response (ARMER): POLST registry access by radio to a POLST call center, where authorized health providers would access (through a portal/web browser) the POLST registry and relay back if there is a POLST and its contents. This method would primarily be used by EMS when cellular phone is not an option and also provides a safeguard to ensure statewide access.
14. Develop both a process for electronic submittal of POLST to the registry, either through the EHR or POLST portal using health information technology standards, and a process for manual input by POLST registry staff to account for the digital divide.
15. A health care professional who honors a POLST in the registry, even if the information is relayed via cellular phone or ARMER, should be immune from liability for following the POLST in the registry, so long as the health care professional believes “in good faith” that the POLST is valid and that it has not been voided.
16. The POLST registry needs quality controls and internalized logic to ensure accurate, timely, and complete POLSTs. Areas of focus may include, but are not limited to:
  - a. Verification that the person signing POLST holds the correct current licensure (i.e., physician, advanced practice registered nurse, or physician assistant licensure).
  - b. Prompt submittal of the information to the registry and approval/verification by POLST registry processes.
  - c. Confirmation of the validity of POLST information.

- d. Deduplication of individuals in registry and identification of current information.
  - e. Reconciliation of POLST registry against recent deaths using state death records.
  - f. Process for removal of POLST no longer consistent with wishes of patient or surrogate.
17. Existing POLSTs need to be populated into the registry by the provider's organization prior to launch. A measure should be developed to ensure the registry is adequately prepopulated before going live.
18. All valid POLSTs should be added to the registry in a prompt manner unless the individual requests to opt-out of the registry. Policy levers and/or incentives may be needed to achieve this the prompt submission.
19. An individual may decide to opt-out of participating in the POLST registry. In this case the POLST remains valid. Anyone who initially decides to opt-out should be able to opt-in at a later time. There should not be a penalty for individuals who choose not to participate in the registry.
20. POLST registry privacy and security policies and procedures must include, but are not limited to, the following components:
- a. Data security regulations and standards which may include HIPAA Privacy, Security, and Breach Notification Rules.
  - b. Risk assessment, analysis, and management and other administrative and technical security controls that prevent, detect, and respond to a breach or attack, address exposed vulnerabilities, and address ongoing security maintenance activities.
  - c. Minnesota-specific laws, including privacy laws.
  - d. Industry standards as applicable.
21. The POLST registry will align to the most recent national and state health information technology (HIT) standards and policies to achieve interoperability, improve quality, and leverage national and state activities. Examples of standards and resources for consideration, include but are not limited to:
- a. HL7 CDA R2 Implementation Guide: ePOLST: Portable Medical Orders About Resuscitation and Initial Treatment, Release 1 - US Realm.
  - b. Post-Acute Care Interoperability (PACIO) Fast Healthcare Interoperability Resources (FHIR) Profile.
  - c. Interoperability Standards Advisory (ISA).
  - d. United States Core Data for Interoperability (USCDI).
  - e. National POLST Technology Guide.

## **POLST Registry Call Center**

22. The POLST registry call center needs two methods for contacting the call center and ensuring statewide access. The methods are:

- a. Cellular phone/phone when internet or mobile broadband are not an option.
- b. Radio using the existing statewide radio system (the Allied Radio Matrix for Emergency response (ARMER)) when cellular phone is not an option.

Both options would primarily be used by EMS and also provide safeguard access for all authorized users.

23. The POLST registry call center could leverage current communication systems used by EMS and health care.
24. The POLST registry call center needs a process to confirm the caller is an authorized user with a recognized need for access, have 24/7 staffing, and adhere to privacy and security laws and requirements.

## POLST Program Administration & Funding

### Program Administration

25. The POLST program requires a coordinating organization with the necessary infrastructure to house and administer the program. The coordinating organization could be either a governmental entity or a non-governmental entity and needs to ensure accountability and alignment between the program components. This organization could house all components or contract out to partners or third-party vendors. The lead organization is responsible for and should be capable of:
  - a. Implementing the recommendations of the MN POLST Registry Advisory Committee, as applicable.
  - b. Developing and implementing strategic and operational governance such as decision-making processes, complaint processes, establish policies and procedures, ensure legal and regulatory compliance, align with existing standards, and define use cases, usability needs, workflows, and data definitions.
  - c. Facilitating an effective statewide POLST coalition to ensure engagement and collection of input from partners including but not limited to POLST Minnesota, Minnesota Department of Health, Minnesota Department of Human Services, Board on Aging, Minnesota Palliative Care Advisory Council, Emergency Medical Services Regulatory Board, MN e-Health Advisory Committee, Minnesota Medical Association, associations from across the care continuum, Honoring Choices, and others.
  - d. Assessing quality and other measurements for success.
  - e. Ensuring that any vendors and/or technical solutions comply with state and federal laws relating to data privacy and health information exchange.
  - f. Assuring the POLST program and components aligns with national and state best practices.

26. The coordinating organization should, with stakeholder feedback and/or guidance, identify an entity to house the registry. This entity to house the registry could be but is not limited to:
- a. State agency
  - b. Non-Profit/Foundation
  - c. Private Entity
  - d. Academic Institution
  - e. Collaborative or public-private partnership
  - f. Health information exchange organization
27. TBD: For a state agency to house the POLST program, the following must be considered
- a. State procurement process required
  - b. Chapter 13 implications <TBD>
  - c. Minnesota Health Records Act implications <TBD>

## Funding

28. Public and private funding will be needed to implement and sustain the POLST program.
- a. One-time and ongoing public funding is needed to support program implementation and maintenance. This includes the registry, call center, and education and training.
  - b. Ongoing private investments will be needed by organizations that access the POLST registry and provide POLST access to patients. Examples of areas of private investments include but are not limited to upgrades to EHRs, organizational readiness for POLST and POLST registry, staff time for POLST and registry training, updates to organizational workflows and policies, and subscription fees to health information exchange (HIE) services.
29. Philanthropic funding could be used for any part of the POLST program.

## Complementary Recommendations

The following recommendations are not necessary for the development and implementation of the POLST program but are complementary to the above recommendations.

30. Research could be a permitted purpose for use of POLST registry information. Considerations for research must include consent, equity, representation, and impact. Areas of research should inform practice and public policy decision making in population and gerontological health and aging, and could include:
- a. POLST decision durability (e.g., frequency and triggers of change).
  - b. Patients' rights, concordance with treatment orders, and bioethical implications.
  - c. Health care professionals' experiences with/knowledge of POLST.

d. Associations between POLST, outcomes, and socio-demographic characteristics and/or risk factors.

e. Health disparities by race/ethnicity, geography, etc.

31. The Minnesota legislature and state agencies should implement strategies to 1) assess and improve payment and reimbursement models for palliative care, 2) grow the primary and secondary palliative care workforce, and 3) increase palliative care training as identified by the 2023 Palliative Care Advisory Council Annual Legislative Report and previous reports. Areas of particular interest include but are not limited to:

a. Enable Minnesota's Medical Assistance and MinnesotaCare to pay for high-value services such as palliative care and advance care planning to benefit those with serious illnesses or life-limiting conditions using existing CPT or HCPCS codes.

b. Explicitly incorporate palliative care into existing Medical Assistance and MinnesotaCare waiver programs that focus on high need patients.

c. Consider making palliative care coverage a requirement for all Medical Assistance and MinnesotaCare managed care contracts in the next contracting cycle.

d. Consider adding palliative care coverage requirements in all settings to Medical Assistance and MinnesotaCare managed care organization contracts, including special considerations for pediatrics, adolescent, and young adult, and perinatal.

e. Establish or expand reimbursement programs or loan forgiveness for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Work, Chaplain, Child Life Specialists).

f. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.

g. Require medical schools to include minimum standards for primary palliative care education for all students.

h. Require physician residencies to include minimum standards for primary palliative care education for all residents.

i. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.

The Minnesota POLST Registry Advisory Committee recognizes that many if not most of the recommendations in the 2023 Palliative Care Advisory Council's annual legislative report support POLST as part of Palliative care and are complementary to the POLST recommendations.